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Spaces and Societal Interactions: Foundations of the Critical Disabled Cultural Lens of a Child of Disabled Adults

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by

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SPACES AND SOCIETAL INTERACTIONS:

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CoDisA are present on our campuses, but not present within research. This autoethnographic study focuses on providing the foundation of the critical disabled cultural lens of a Child of Disabled Adults (CoDisA) for future study of CoDisA within higher education research. The findings of spaces and societal interactions are presented through the accessible format of autoethnodrama. This two act show is a fun and immersive way to take you on a college tour trip “up the 5," from San Diego, California to Rohnert Park, California in Sonoma County. Act 1, the findings chapter with thorough scene descriptions, helps frame where the general findings of spaces and societal interactions take place. The scenes themselves feature rich, descriptive findings of kindness not always being kind, forced intimacy, stigma, and the ways physical space made me feel at home or like a stranger due to my cultural foundations. Act 2, our discussion chapter, then creates dialogue between the characters of Young, Teen, and Adult Amelia-Marie, and audience members: a student affairs professional and a researcher. This chapter, styled like a theatre talkback, addresses how this study compliments and contrasts existing literature, the recommendations of practice, one example being using identity-first language, and recommendations for research, one example being further investigation of disabled culture present on campuses.

Contents

Dedication

To the 1984 World Series wheelchair section for bringing my parents together.

To my father, Gary Altstadt, for being my fantastic Papa. As you have retired from your career in K-12 educational administration, mine in Student Affairs is beginning. Thank you for all your wisdom, support, and love that you provide.

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To my grandma, Virnell Foster, who never had formal education beyond 8th grade, but is a lifelong voracious reader and learner.

To my grandfather, John Raymond Romero, who sends the best encouraging emails.

To my late grandfather, William “Bill” Altstadt, I’m proud to be a Husker like you.

To my late grandmother, Maxine Altstadt, who made his education possible.

Finally, to all CoDisA.

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Introduction

Arriving at Sonoma State University was a relief after visiting University of California, Santa Barbara and University of California, Santa Cruz. I remembered when my family drove through the UC Santa Barbara campus, late summer sunlight sparkling off the blue Pacific as we headed north to Sonoma State. When we stopped at UC Santa Cruz, the winding, steep roads made it clear that there was no way my spinal cord-injured and wheelchair-using parents were going to be able to get out of the car and explore the campus, to peek around the dorms or explore any of the academic buildings. Not to be deterred, with a signed "Love You" from my mother to mark the start of our exploration, my brother and I got out of the car to poke around ourselves. We were the only ones on campus, other than the wide eyed deer we spotted behind a building, as I assessed whether I liked this campus enough to apply. As the fog rolled in through the trees we hurried back to the car, parked predictably in an accessible parking spot. With hand controls pressed gently against the brake, my mother drove our family down the mountain. While watching the sky turn to oranges and pinks, I thought about how much walking it would take to hike to my classes every day here.

Sonoma State University, by contrast, was wide open and flat; there was never a question that my parents would be able to explore every building on campus with me. Our car pulled smoothly into an accessible spot right at the front of campus, close to the curb cut in the sidewalk. As we piled out of the car I looked around and smiled brightly, ready to explore with my family.

Our cultural lenses are shaped intimately by our relationships to family members. The professional field of Student Affairs acknowledges this reality from many different angles such as race, gender, sexuality, and generation of college attendance. Students enter higher education with their family structure influencing how they approach higher education institutions. Being a Child of Disabled Adults (CoDisA) meant when I went to visit colleges I was looking around for

ramps, for the nearest elevators, and ways that we could explore together. This cultural evaluation depended upon the spaces and societal interactions I experienced leading up to higher education. It is from this perspective that I am conducting this research.

Children of Disabled Adults (CoDisA)

Children of Disabled Adults, or Child of Disabled Adult(s), from here on out referred to by the shortened form CoDisA, are defined to be any child who has at least one parent or guardian who is disabled before or during their developmental years of childhood. A CoDisA's relationship to disability is different from any other familial relationship, as parents and/or guardians shape our development throughout childhood. This term does not exist anywhere that I have found in literature, so I am coining this term for the use of my thesis and beyond, as a new disabled cultural term. Within Chapter Two, the literature review, I further describe the roots of Deaf culture which inspired this acronym. Within Chapter Three, the methodology, I describe more of the connections that I have personally within Deaf culture due to my mother.

Prevalence of Disability Within the United States of America (USA)

Disability has a broad definition which encompasses more than physical and visible disabilities, which is a comprehensive definition that must include the predominant perception of disability. Disability includes "issues spanning physical, systemic, cognitive, hearing, developmental, or a mix among these" (Kirshbaum & Olkin, 2002). The Americans with Disabilities Act (ADA) of 1990 guarantees work and school accommodations to disabled people (Department of Justice, 2010). The legal requirements of ADA only lay a basic foundation when considering the civil rights of disabled people to accessibility at higher education institutions. Institutions can be unwelcoming and uncomfortable spaces (Dolmage, 2017). As recognition of disability grows, so does our need to understand the disabled cultural lens and the impacts of this lens in relation to higher education.

One in four adults in the USA has a disability, which is 25% of our total population (*CDC*, 2019). The latest research estimates that in the USA disabled parents could be as many as 6.9 million people (Kaye, 2012). Due to the age of this study, these children under the age of 18 are present at our higher education institutions.

Formation of Disabled Culture and its Social Impact

The disability civil rights movement having gained momentum beginning in the 1960's accelerated the formation of disabled culture. The disability civil rights movement is constructed in direct opposition to ableism, defined as "the process of favoring, fetishizing, and building the world around a mostly imagined, idealized body while discriminating against those bodies perceived to move, see, hear, process, operate, look, or need differently from that vision" (Taussig, 2020a, p. 10). By the early '90s the disability civil rights movement advocated for the implementation of the ADA- landmark legislation protecting the civil rights of disabled people signed into law on July 26, 1990, by President George H.W. Bush. (Department of Justice, 2010; Shapiro, 1993). This legislation recently had its 30 year anniversary. This societal shift in the aggregation of the disabled civil rights movement was bound together by the acceptance of difference, as disability cannot be siloed to any one section of the population (Shapiro, 1993)**.** As it is such a large population, language has also changed over time.

Language within the disabled community has rapidly shifted from the 1960's to the present. Person first language was once the preferred language when referring to disability, having roots in the original disabled civil rights movement (Shapiro, 1993). Person first phrasing emphasizes personhood rather than disability. An example of person first language is "person with a disability." While person first remains acceptable language, there is now a strong community and cultural preference for identity first language. An example of identity first language is "disabled person." Identity-first language emphasizes disability as a social construct, but more than that- an identity one can claim proudly (Abes et al., 2019). Anything outside of

person first or identity first language for disability, such as euphemistic language like “differently abled," actively undermines the intentionality of humanizing language like “disabled." I will be using identity first language throughout my thesis in accordance with viewing this research through a disabled cultural lens.

COVID-19 and the Increased Risk for Long Term Disability

Writing this thesis from home in 2021, it would be neglectful to not mention the impact of COVID-19 on the USA. COVID-19 has killed, at the time of this writing, upwards of 609,012 individuals in the USA (CDC, 2020). However, what I must address is what happens to those who recover from COVID-19 and suffer from post-acute sequelae of COVID-19 (PASC), also known as being a “long hauler” (Komaroff, 2020). “Long hauler” is a euphemism for disability, as the people who recover experience long-term symptoms such as “fatigue, body aches, shortness of breath, difficulty concentrating, inability to exercise, headache, and difficulty sleeping” (Komaroff, 2020). Whether or not these acquired long term disabling symptoms are temporary or permanent is unclear. Previous widespread debilitating illnesses, such as rubella and polio resulted in deafness and paralysis, respectively (Shapiro, 1993). With a reported total of 34,548,847 cases of COVID-19 in the USA the chance of recovery comes with an increased long-term risk for disability (Komaroff, 2020). This affects multiple generations of people. Adults included in these numbers do have children or may want to have children in the future. Institutions of higher education must understand and prepare to meet these social and cultural needs.

Purpose Statement

This study focuses on spaces and societal interactions viewed through the critical disabled cultural lens of a CoDisA with the aim of providing a foundation for future study of

CoDisA within higher education research. This was researched through autoethnography, and the findings are presented through autoethnodrama.

Research Questions

1. What has my experience been as a CoDisA?
2. What are the salient experiences of a CoDisA through a critical lens?

Why This: Significance of Study

CoDisA are present on our campuses, but not present within research. There is little to no research of the CoDisA population in any field so adding research to specifically the field of higher education is significant and long overdue. Additionally, disability affects not only the disabled person, but CoDisA. The United States is currently grappling with the novel coronavirus COVID-19 and what impact that disease will have on recovered individuals (Komaroff, 2020). This disease may well increase disabled parenting in our next generations of students, much like previous disease outbreaks such as polio and rubella also caused disabilities to occur in those individuals experiencing PASC (Komaroff, 2020). This study will provide a needed foundation for future higher education research on CoDisA as disability studies and its intersections will be increasingly important in addressing disabled social and cultural needs throughout higher education.

Research Design

Autoethnography in Brief

The methodology I have chosen to use is autoethnography, which is a reflexive form of ethnography. Ethnography is defined as "'the various ways different groups go about their lives and to the belief systems associated with that behavior'" (Wolcott, 2008, as cited in Merriam, 2016, p. 29). The subjectivity of this methodology is a strength and appropriate to provide

foundations for this new subject area. Autoethnography subverts expectations of objectivity within research and uses intimate knowledge of culture to deepen validity of research. Autoethnography actively centers the voice of minoritized populations, to address their population from an insider perspective.

Centering My Voice With Autoethnography

Autoethnography as a methodology was captivating from when I was made aware that it existed during my first research methods course with my advisor Dr. Stephanie Bondi, Associate Professor of Practice and Student Affairs Administration M.A. Coordinator, at the University of Nebraska. Upon entering graduate school, I resisted being drawn to disability studies. When I did decide to explore the idea of the CoDisA population within research I was disappointed, but not necessarily surprised, that there was very little information about those with experiences like mine. So, it follows that focusing on my own experiences through autoethnography was one way to fill the void. Autoethnography is research which can center minoritized experiences and subvert oppressive discourse put onto a population from outsiders to culture (Mertens, 2020). This is a needed choice of methodology when it comes to research on disabled populations, due to marginalization and objectification (Couser, 2005). In this case, I am sharing my experiences of being a CoDisA through a critical disabled cultural lens, having used the social model of disability and the pedagogy of the oppressed as frameworks to guide the study. Both frameworks are described in Chapter Two in more depth. By adding to this literature through autoethnography I am giving myself a voice while calling on others like me to find their own.

Autoethnography is research that does not pretend to be unbiased while sharing a truth. I have had concerns about how to tell my stories, truthfully. I was not taking notes throughout my life— I lived it. Ellis and Bochner (2000) cover autoethnography and particularly what it means to be truthful. Those who know me may not have seen stories they were also part of from my perspective, but that does not make my stories any less truthful. I have previously written

stories as part of an autobiography or part of a memoir. If I wrote any of those stories again today, I would write them differently. However, those stories are still my truth and if I rewrote those stories today, those would also be my truth. What this autoethnography comes to be will also be my truth. I want readers to come with me as I delve deep into the central aspects of me as a CoDisA pursuing higher education. I hope through my reflection, dear reader, that you consider what your truth is as well in relation to my stories.

Autoethnodrama: Presentation of Findings

Ethnodrama is defined as a written play script consisting of dramatized, significant selections from data collection (Saldaña, 2011, p. 13). Often research findings are presented in a narrative format. However, for this thesis, I wrote the findings in the form of a script that takes the analyzed data and displays the data through exhibition of scene descriptions, narration, and dialogue (Saldaña, 2011, p. 206). I changed my presentation of findings from a traditional academic chapter to ethnodrama because a play is more accessible reading for many individuals and invites readers into an immersive experience of the findings.

Theatre conveys information in a compelling manner, meant to entertain and to educate through rich descriptions presented through text and production. Original autoethnodramatic work goes against the ideas of fictional theatre, which generally requires a suspension of disbelief, to having the audience assume belief in the truth presented by the autoethnodramatist (Saldaña, 2011, p. 24). I was influenced by theatre that would not define itself as ethnodrama but would be considered such under this academic definition used to legitimize the presentation of findings through arts-based research (Salvatore, 2017, p. 268). Some of my influences when constructing the presentation of my findings are Alison Bechdel's *Fun Home*, Moises Kaufman's *The Laramie Project*, and Eve Ensler's *The Vagina Monologues*. These shows, the latter two that I have been in as a cast member, are rooted in reality, rather than realism (Saldaña, 2011, p.

14). This presentation of findings conveys the truths of my autoethnographic study in the authentic reality of my experiences.

Strengths of Research

The strengths of this research are that the findings are presented through a nontraditional format, the study uses an underutilized means of research, and details rich stories about minoritized experiences.

The findings being presented through a nontraditional format like autoethnodrama is a compelling and interesting reason to engage with this research, beyond the subject matter. The presentation through a play can help readers feel more personally connected to, and be influenced by, the stories being told (Saldaña, 2011, p. 16). A script, or performance, can better reflect setting and emotions than traditional narrative academic writing. That personal connection is an exchange between the actors and audience which brings attention, life, and depth to experiences.

The underutilized research method of autoethnography is a strength of this research because my knowledge actively contributes to the field of higher education research, as well as disability studies research, from my perspective as a CoDisA. The approach centers minoritized voices. Although anecdotal stories are useful, research studies are an interaction between past studies and current studies, highlighting much needed diverse perspectives in academia.

Centering minoritized identities can be done in many ways, but the strength of this research is by doing reflexive research on myself through my own lens, I have the opportunity to share, create, and convey the rich stories of my disabled cultural experiences within being raised in a household led and directed by disabled adults: my mom and dad. The subjectivity of autoethnography is important because the subjectivity of my experience allows for the creation of this foundation in the absence of established research. This centers more than my voice, but

those who identify with the stories I share. This centering reflects the world we already live in, filling the gap of formal knowledge within research, highlighting it within the academic field for further research and reflection.

Limitations of Research

The limitations of research are the time period of data collection and findings and the lack of previous research.

Over the course of my graduate program beginning in Fall 2019, I discovered the lack of research on the CoDisA population. The research began with a prospectus in Spring 2020, and data collection was completed in early February 2021. Findings were compiled and written by June 2021. This is a short time frame for foundational research. The short time frame that this research was conducted in is a major limitation to the depth of research as there were preliminary limited findings that had to be cut due to the limitation of time.

The lack of recorded previous research and knowledge is a contributing limitation to conducting research. If there was more foundational literature on CoDisA I would have been able to delve deeper into a literature review about CoDisA to establish the foundations of being a CoDisA. More literature would have allowed me to form a less general framework to design my study. The current study allowed me to explore and record the foundations of my experiences and share that with readers.

Summary

Chapter One introduced the concept of Children of Disabled Adults (CoDisA) while covering the prevalence of disabled parents and the limited research available on CoDisA. Disabled parents are more relevant than are researched, as one in four adults in the United States are disabled. There is limited research available on CoDisA as a population because most

research on disabled parents is focused on the disabled parents themselves, not their children's perspective.

The purpose of the study is to research and convey the salient experiences of one CoDisA through the method of autoethnography, or a reflexive study of culture. This study designs assists in centering minoritized voices in research, reflecting the world around them.

The findings presented in the nontraditional format of autoethnodrama for access and interest of the reader, as well as to provide rich, thick description of the experiences of the author in a different approach than narrative inquiry.

The strengths of this research are that the findings are presented through a nontraditional format, that it explores an underutilized means of research, and details rich stories about seldom documented or researched experiences. The limitations of research are the time period of data collection and findings and the lack of previous research.

The big ideas to carry through to the reading of the next chapter is the introduction of a significant reason for this study, a knowledge and research gap, and the reason autoethnography is the proper method to fill this gap is so that, with my experiences, I can provide the suitable knowledge for formal research. Additionally, I present this knowledge in a nontraditional format that will engage readers' interest and learning.

In Chapter Two, the studies that have been done are discussed and theoretical frameworks are explored.

Chapter Two: Literature Review

This literature review goes into depth of subjects that I reviewed- all of which are outside of the scope of higher education research due to the research and knowledge gap with the subject of CoDisA. The literature covers the inspiration of the term CoDisA, disabled parenting, the limited research on CoDisA, different types of stigma, and the common theoretical perspectives within literature which I considered versus those I used for this study.

Children of Deaf Adults (CoDAs)

The coining of the shortened form of CoDisA is directly inspired by and owes its thanks to CoDAs, who represent a small but significant part of the Deaf community and Deaf culture; it would be remiss and offensive to not identify the influence. Deaf culture is a defined community and culture separate from other disabled communities and cultures, with their own terminology and historical struggles. Since Deaf culture is so heavily defined, I have chosen to not include specific literature about Deaf and HoH individuals and CoDAs, but rather to focus on a wider breadth of disability culture and not erase distinctions between disabilities that have been well defined. Within Chapter Three, the methodology, I describe more in depth the connections that I have had with Deaf culture from childhood. Although CoDAs could be considered underneath the umbrella of CoDisA by an outsider to the culture, it is not common that a culturally Deaf or Hard of Hearing (HoH) person would consider themselves disabled. I make this distinction about being culturally Deaf because there are “little d” deaf individuals who might consider themselves disabled, the capitalization of Deaf notating this involvement of identity and culture. CoDA has cultural significance and has been long established in Deaf culture. It is incredibly important to be respectful of Deaf culture and note that CoDisA is not interchangeable with CoDA when it comes to referring to children of a Deaf adults.

Limited Research Relevant to CoDisA Population

While searching through the literature one aspect was apparent: there is not much research available on the topic of CoDisA. All studies reviewed were outside of the scope of higher education research, as none could be found within the field. Most studies reviewed fell into the fields of psychology, health, or child development. Additionally, even casting a wide net among different fields to find relevant research there are only a few studies which touch on the exact subject of CoDisA (Jacob et al., 2019; Krauss & Olkin, 2019). Within that, there is not enough focus on the differences between disabilities (Kirshbaum & Olkin, 2002). Disabilities can range from mental to physical, as well as vary in severity. Specific differences with Deaf populations are noted within more generalized literature, but not studied or separated within literature on disabled parents. The lack of distinctions within disabilities makes it difficult to obtain any very specific data within this larger population and can generalize information across very different experiences.

While the aforementioned emerging research focused on CoDisA, which is similar to my study, it is not research within the field of higher education or focused specifically on CoDisA students. All previous research has been done within the fields of psychology and health, instead of the specific context of higher education as I do in this thesis. The findings of these studies found that "a majority of young adults who participated …reported having positive self-esteem, perceived relatively low stigma of having a parent with a disability, and had a positive overall experience growing up with a parent with a disability" (Jacob et al., 2019, p. 316). Another study expands on the experiences of CoDisA but is limited in scope due to being exploratory research (Krauss & Olkin, 2019). The Krauss & Olkin study concluded that perceived stigma impacted negative outcomes for children with disabled parents, but that the same strategies used to help disabled individuals—such as integration of a positive disability identity and affiliation with a disabled community—could benefit family members (Krauss & Olkin, 2019, p. 7). These studies

support the idea that CoDisA have positive experiences with their parents despite negative opinions held by others. One way to challenge this lack of distinction, negative opinions, and research is to look directly to disabled authors for their experiences.

Disabled Adults on Disability and Parenting

Two disabled researchers rose to the top when having direct accounts from disabled adults who are also parents. Dr. Rebekah Taussig wrote her dissertation and turned that work into the memoir "Sitting Pretty" (Taussig, 2020a). Dr. Bobby G. Greer wrote a research article named "Children of Physically Disabled Parents: Some Thoughts, Facts, and Hypotheses" (Greer, 1985). Both parents actively challenge deficit perspectives when considering parenting while disabled, such as the assumption that disabled people should not have children and the assumption that CoDisA would be providing caregiving if they were born to disabled adults.

Assumption of Lack of Capability

Dr. Rebekah Taussig wrote a memoir based on her own experience as a disabled woman in the Midwest, bringing in stories and rhetorical questions to help frame what an ordinary life of a disabled person is like. Her chapter on what it means to be a disabled woman in particular says how no one dared to ask her if she wanted children- with the assumption behind the lack of a question being either lack of the capability of her body to conceive or the lack of capability for parenting (Taussig, 2020a, p. 150). Taussig also says frankly that deciding to have a child as a disabled woman is more difficult than simply wanting one, not knowing if she could even conceive (Taussig, 2020a, p. 150). However, she surprises readers after stating these concerns in the postscript that not only was she pregnant, but that her husband had been diagnosed with colon cancer—all while COVID-19 was coming into our worlds (Taussig, 2020a, p. 231). Their child, Otto, was born May 22, 2020, and is a happy, healthy baby (Taussig, 2020b, 2021). By sharing further mini-memoirs through Instagram, she challenges the assumption of a lack of capability of parenting.

Assumption of Caregiving

The pervasive assumption in the literature is that CoDisA are overburdened or inappropriately engaged in caregiving (Kirshbaum & Olkin, 2002; Olkin et al., 2006; Pakenham et al., 2006). Although children can act in the caregiving role, CoDisA are not necessarily the same population as those who care for disabled adults. which not only handled parenting from the perspective of the disabled parent, but also challenges the assumption of caregiving even within a "physical superiority" of the child (Greer, 1985, p. 138; Merchant & Coriell, 1980, p. 20). He references himself as "the author" with a physical disability within this article. Dr. Greer has cerebral palsy. This is an important context to have in order to understand the nature of his disability and the perspective that he was providing about disability. I was cautious about how disabilities can be lumped together, but the experiences among different disabilities can be quite diverse.

Greer addresses that although his son "who is more dexterous at twelve years of age than his father, does not yet match his father in strength and experience," implying that there is a tradeoff rather than overburdening care—not that their child would view it that way (Greer, 1985, p. 183). Greer, being a disabled parent themselves, even suggests another perspective that by having some reliance on their child for help, even if to save time rather than a consideration of ability, may increase that child's feeling of competence (Greer, 1985, p. 138). More recent literature suggests this is accurate as adolescents are less likely to view helping out their parents as a "negative disability event" than the disabled parents themselves (Mazur, 2008, p. 10). It is more likely for a disabled parent to have concerns of asking for help from their child, than for a child to feel as if they are being overburdened (Greer, 1985; Mazur, 2008). This leads to parents asking for less help overall, to avoid overburdening their children, due to perceiving asking for that help as a negative event.

Dr. Taussig's memoir, and Dr. Greer's chapter, touched upon the types of stigma, via the assumptions made about themselves as parents and the way they challenge these assumptions, that can be experienced when disabled or raised alongside disability.

The Three Kinds of Stigma

There are three kinds of stigma found within the literature: public stigma, self-stigma, and courtesy stigma. The common factors of stigma are stereotypes, prejudice, and discrimination (Corrigan & Watson, 2006, p. 37). The type of stigma that most impacts our population of CoDisA is courtesy stigma, but all three kinds of stigma are discussed.

Public Stigma, or Stigma

The foundational literature defined stigma as "a social process where individuals with certain attributes are rejected by others" (Goffman, 1963, as cited in Krauss & Olkin, 2019, p. 2). Follow up literature continues to highlight an important influence on stigma, which is power.

> Stigma is entirely dependent on social, economic, and political power—it takes power to stigmatize. In some instances, the role of power is obvious ….. When people think of mental illness, obesity, deafness, and having one leg instead of two, there is a tendency to focus on the attributes associated with these conditions rather than on power differences between people who have them and people who do not. (Link & Phelan, 2001, p. 375)

An example of public stigma, a power play in action, is forced intimacy. Forced intimacy is defined as being pressured or coerced to reveal personal information to gain access to basic resources or accommodations (Mingus, 2017). This power dynamic connects with Freire's work, struggling for humanization, detailed later on in this literature review. Stigma keeps oppressed populations within their relationships with oppressors, as the "lacking" is centered within a lack of ability to think, want, or know rather than a larger systematic issue—which can be external or internal (Freire, 2000, p. 60).

Self-Stigma, or Internalized Stigma

Self- stigma, or internalized stigma, shares a similar definition to stigma, or public stigma. Although stigma might be easier to spot when public, stigma is not restricted to an external viewpoint. Instead of coming from an outside source, not part of the group, stigma is being perpetuated by the self. Self-stigma is connected to public stigma but can be experienced separately from public stigma as well. "Depending on the situation, persons with mental illness may respond to stigma with low self-esteem and diminished self-efficacy, righteous anger, or indifference" (Corrigan & Watson, 2006, p. 47). If they experience low self-esteem and diminished self-efficacy, they may develop self-stigma (Corrigan & Watson, 2006, p. 35). Self-stigma, as an example, can look like negative self-talk as in telling oneself that they are useless- even if there is outside evidence to the contrary. Self-stigma is different in origin from stigma encountered by association to disability.

Courtesy Stigma

CoDisA encounter courtesy stigma. While stigma is experienced by individuals of minoritized populations, research neglects to focus on how stigma is not only focused on the minoritized person, but those who are associated with them. Courtesy stigma comes by the way of being related to individuals who are stigmatized either by close family relationships or through their occupational or social activities (Green, 2007, p. 332).

CoDisA are raised around stigma against their parents and experience courtesy stigma during their development. Courtesy stigma looks like pitying disabled people by virtue of expressing sadness, or nervousness when interacting with a disabled person (Alexander et al., 2002; Green, 2007). Courtesy stigma occurs from influence in society, as physical disability by itself does not negatively impact CoDisA in adjustment, attitudes, gender roles, or family functioning (Alexander, et al., 2002, p. 28). The level of courtesy stigma varies based on the disability, or other minoritized identities, as it relies on the opinions of those interacting with

minoritized identities (Jacob et al., 2019, p. 316). Courtesy stigma leads us into a discussion on the different ways you can approach disability through research lens, to challenge or affirm the influence stigma has on disabled people and CoDisA.

Considered Theoretical Perspectives

Deficit Model of Disability

The majority of older literature focuses on the deficit model when it comes to researching disabled parenting. Researchers and clinicians have assumed without basis that physical disability negatively influences parenting (Altschuler & Dale, 1999; Lundwall, 2002, as cited in Mazur, 2008, p. 4). It is surprising to many that disabled people would like to have children, or that they are sexual humans at all (O'Toole & Doe, 2002, p. 90). Due to these assumptions, older literature has perpetuated the idea within research that disabled adults are incapable of parenting. Disabled adults experience increased prejudice about their rights or abilities to parent (Hohmann, 1981, as cited in Kirshbaum, 2000, p. 67). A deficit model like this focuses solely on the negative impacts of disability, and a belief that disability is inherently negative. This effectively contributes to the erasure of studying the impact and insight of CoDisA.

Literature falling into the deficit model is dismissive of the capability of disabled parents. Literature has focused on the negative aspects of having to navigate caring for a child as a disabled parent, and in particular young children (Kirshbaum, 2000). Professionals questioned the ability of parents, as if they were unaware of the implications of their own disability on raising children (Kirshbaum, 1981, as cited in Kirshbaum, 2000, p. 69). The deficit model does not give an opportunity to explore what can be gained by being a CoDisA. I did not use this theory as a framework, as it does not reflect my lens while designing the study.

DisCrit

Disability Critical Race theory is an important addition to the field because disability is often framed to oppress individuals "at the margins of Whiteness and ability" (Annamma et al., 2018, p. 47). DisCrit is a multidisciplinary theory developed around Black feminist literature which address inequities in the law. DisCrit expanded Critical Race Theory to involve the intersections of disability and race. When applied to education, this theory more deeply reveals inequalities perpetuated by privileging ability and Whiteness. For example, privileging ability looks like not having to search for a way to enter a building, while privileging Whiteness looks like not being questioned for entering a building. The intersection of privileging ability and Whiteness looks like getting questioned and accused of faking a disability when entering a building through an accessible entrance. Although I will not be going into depth surrounding this theory, it is important to keep in mind as most literature frames itself, intentionally or not, around white disabled individuals. I did not use this theory as a framework for this study due to the time limitation involved in research.

Crip Theory

Crip Theory is a theory created by Robert McRuer, a gay man, who draws connections between queer identity and disabled identity. The theory draws connections across many mediums and global factors (McRuer, 2006, p. 70). The theory is useful when it comes to centering disabled identity emergence. This is applicable when it comes to considering the impact of identity of CoDisA. Crip Theory examines the effects of the world on minoritized identities, rather than assuming deficit within disability or queer identities (McRuer, 2006). The theory says that the invisibility of the identities of able-bodiedness and heterosexuality are interwoven.

Compulsory Able-bodiedness and Performativity. "A central concept of crip theory is compulsory able-bodiedness and able-mindedness" (Abes et al., 2019, p. 65; Kafer, 2013; McRuer, 2006). The idea that compulsory able-bodiedness and able-mindedness produces disability is a powerful one, as it places the onus upon systems and expectations rather than the disability or identity within itself (McRuer, 2006, p. 2). This is a fluid cultural concept, rather than a hard and fast rule. Within either compulsory state the difficulty is to question unspoken assumptions, especially when the people asking do not know that they hold such assumptions (McRuer, 2006, p. 2).

Performativity originates from the idea that people should strive to be perceived as close to the ideal assumption that compulsory able-bodiedness or able-mindedness holds. Since this concept is based on perception, rather than reality, disabled people are expected to hide disability in favor of being perceived as able even as society is built to increase issues of disability. This places a negative connotation upon being disabled and uplifts the idea that being able is the ideal (McRuer, 2006, p. 19).

Robert McRuer: Flawed Ally, Not Authority. McRuer credits in the foreword of *Crip Theory* that the beginning of his studies began with disabled scholar Rosemarie Garland-Thomson (Garland-Thomson, 2016). She authored the 1997 foundational disability studies work *Extraordinary Bodies* and inspired the path McRuer would take by commenting on how AIDS cultural theory was also disability studies (Garland-Thomson, 1997; McRuer, 2006, p. xiii). Although McRuer's work is transformational, it does not settle right with me for a foundational disabled-queer theory to been named solely after a disabled slur and named by a nondisabled person. "Crippled" is a slur against the disabled. Although this can be viewed as similar to the reclamation of queer from a slur, especially in a book discussing the cultural signs of queerness and disability, the issue emerges that Robert McRuer does *not* identify as disabled anywhere that I can find after 2006, and specifically reveals himself to be HIV-negative in Chapter 1

“Coming Out Crip” (McRuer, 2006, p. 57). Even if he was surrounded and supported by disabled individuals in this work he has, in my eyes as a disabled person and CoDisA, overstepped by naming this analysis “Crip Theory." Crip is not his word to reclaim. The slur seems to be used for the shock factor rather than as a description of disabled-queer experiences from disabled-queer points of view (McRuer, 2006, Chapter one: Coming out crip). He consistently refers to the slur crip as a “term," similar to queer, which I heavily challenge as someone who is disabled, a CoDisA, and queer themselves (McRuer, 2006, p. 34). McRuer, as a nondisabled person, fails to grasp the deeper cultural implications of the slur. Even with noting the time in which it was published, crip is not a necessarily common identity term to be used in 2006, nor now used in 2020 to describe oneself: the prevailing term being simply “disabled." This reclamation of queer versus crip cannot be conflated.

There is certainly space for allies to teach and help dismantle structures, especially within higher education. Allyship is a necessary tool as McRuer highlights that he teaches classes on how to lead decomposition in disability studies (McRuer, 2006, p. 161). However, this author is a white cis gay man who is able-bodied and able minded. Allyship can be problematic when allies further inequities by centering themselves while not taking risks and not significantly advocating for justice (Patton & Bondi, 2015). Allies are needed to uplift disabled voices, not overtake them.

Later works have also highlighted that *Crip Theory*, in addition to using a slur, privileges visible, physical disability over other disabilities (Abes et al., 2019). This could be attributed to the work being published in the mid-2000’s. The work needs an update to represent the diverse spectrum of disabilities more accurately. This is an additional limitation of being written by a nondisabled individual and a focus on the presentation or performance of identity, originating from the ideas of a body theory reading group mentioned briefly in the acknowledgements (McRuer, 2006, p. xiii).

Ultimately, I acknowledge the major strides at identifying cultural signs of queerness and disability that McRuer's work has accomplished. In the disability studies field as of 2021, my position is that his work is tainted with a lack of ownership and transparency surrounding his nondisabled identity framing this research and analysis.

Chosen Theoretical Perspectives

Social Model of Disability

Recent literature reframes research on disabled adults by approaching through a social model of disability. The social model focuses not on the existence of impairments itself, but rather the attitudes embedded in the socio-cultural context in which interactions between individuals with and without disabilities create the 'problem of disability'" (Green, 2007, p. 336). The social model of disability is the beginning of focusing on how experiences around disability are interpreted. The study included 24% of students who do not have a disability but have a close disabled family member (Green, 2007, p. 336). The stress of managing a household or raising children comes not from disability, but interpersonal negotiations(Iwasaki et al., 2005; Kirshbaum & Olkin, 2002; Mazur, 2008; Strike & McConnell, 2002). The most striking statement of one study focused on a married couple who are both intellectually disabled and have three children together is that "People are always ready to see what you can't do. They are not ready to see what you can do" (Strike & McConnell, 2002, p. 10). This statement also helps highlight the focus of literature being on whether disabled parents are able to care for their young children, rather than on the impact on the children themselves. This study also helps dispel the myths perpetuated by older literature relying on the deficit model. Relying on the social model of disability, the literature is capable of beginning to analyze the societal struggles of disability, rather than putting the onus of challenges of disability on disabled people. The social model of disability intersects well with the pedagogy of the oppressed because both

frameworks have to do with subverting the assumption of deficits and empowering the socio-cultural context surrounding oppressed and minoritized populations.

Pedagogy of the Oppressed

Freire's *Pedagogy of the Oppressed* is a critical pedagogy which lays out the importance of education which originates from the knowledge of oppressed people themselves (Freire, 2000). Although this pedagogy was developed around illiterate adults, a disabling condition, in Freire's home country of Brazil, and has applicability to other oppressed populations. A key term of this pedagogy is conscientização. "The term conscientização refers to learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality." (Freire, 2000, p. 35). This concept is essential to understanding the pedagogy of the oppressed as Freire addresses the importance of humanization, education, and dialogue driving people to go against the oppressive elements of reality. The pedagogy emphasizes the oppressed as the driving population behind a reclamation of humanity, which is integral to uplifting oppressed people.

Humanization. "Freire [...] operates on one basic assumption: that man's ontological vocation (as he calls it) is to be a Subject who acts upon and transforms his world, and in so doing moves toward ever new possibilities of fuller and richer life individually and collectively. This world to which he relates is not a static and closed order, a given reality which man must accept and to which he must adjust; rather, it is a problem to be worked on and solved." (Freire, 2000, p. 32). Freire's focus on humanization is important. In the first chapter he states: "If the humanization of the oppressed signifies subversion, so also does their freedom; hence the necessity for constant control. And the more the oppressors control the oppressed, the more they change into apparently inanimate 'things'." (Freire, 2000, p. 59). By reclaiming their identities, this humanizes them and allows them to not only exist in the world, but to realize

themselves as an active part of the world. Preventing humanization are things like education which does not originate from the oppressed.

Education. Freire cautions against a "banking" style education, in which one party deposits information into another party, perpetuating oppression and lack of critical consciousness (Freire, 2000). Education developed in conjunction with others through dialogue is advocacy. Banking education can lead to critical consciousness as students live out their lives and find the inconsistencies between the lives they live and what they were taught, but it is a drawn out process because of the resistance to dialogue (Freire, 2000) Education that takes a more active role with each member adding to the discussion is much more likely to radicalize students within a shorter amount of time as they build the naming of the world together (Freire, 2000). This is what Freire calls "problem-posing education" which "affirms men and women as beings in the process of *becoming*" through being creative and engaging in reflection and the actions taken in reality, rooted within dialogue (Freire, 2000, p. 84).

Dialogue. Dialogue, continuous dialogue, is the most important element of the pedagogy of the oppressed. Although the oppressed can work to free themselves from their current circumstances, they can fall into the same patterns as the oppressors before them, creating further dependence on the existing systems (Freire, 2000). To avoid this Freire emphasizes conversations must have meaning as well as action to have true dialogue (Freire, 2000, pp. 87–88). The main reasoning behind this plays back into both the concepts of a non-banking education and in humanization, in a profound way: "Human beings are not built in silence, but in word, in work, in action-reflection" (Freire, 2000, p. 88).

Summary

Chapter Two covered the literature review synthesis and the theoretical frameworks surrounding disability.

This chapter introduced the foundation for the term Children of Disabled Adults (CoDisA), the limited research on CoDisA, and disabled adults challenging assumptions made about being a disabled parent. After that section, the three kinds of stigma- public, self, and courtesy- were covered in depth with examples.

Theoretical frameworks such as the deficit model of disability, DisCrit, and crip theory were described and were not used in this study due to limitations of time or dislike of the framework. In particular, the section about crip theory goes into why McRuer's theory was not used instead of the social model of disability, since both contain similar views on how disability is constructed by society.

The frameworks that were used to guide the study are the social model of disability and the pedagogy of the oppressed, covering both cultural and educational models. The social model of disability describes disability as constructed by society. The pedagogy of the oppressed is used to empower oppressed people to use their own knowledge to humanize, educate, and create dialogue.

The big ideas to carry through to the reading of the next chapter is that this study was designed, after reviewing the literature, to push against the deficit model of disability by providing an autoethnographic account of disabled culture, as well as to create literature on this specific topic that is not seen in the field of higher education from the CoDisA perspective.

In Chapter Three, the choice of autoethnography for the research design and autoethnodrama for presentation of findings are discussed. Additionally, Chapter Three goes into my educational background as part of elaborating on my researcher-participant reflexivity.

Chapter Three: Methodology

The methodology I have chosen to use is autoethnography. This is a reflexive form of ethnography, a study of culture defined as "'the various ways different groups go about their lives and to the belief systems associated with that behavior'" (Wolcott, 2008, p. 28 as cited in Merriam, 2016, p.29). This design approach will give critical insight into the identity of being a CoDisA and disabled culture through the lens of the author.

Autoethnography as Design

Autoethnographies are personalized accounts which draw research and data from the research to extend cultural understanding (Wall, 2008). Autoethnography is research from the insider perspective, as you are essentially already in a lifelong field study. "[A]utoethnography has become almost exclusively identified with those advocating the descriptive literary approach of evocative autoethnography" (Anderson, 2006, p. 376). Evocative autoethnography in particular is a fitting design for this research as it focuses on creating an especially thick description of an individual's experiences. One benefit of choosing this design is that the research written in this style can be more accessible to a wider array of people. When I read academic articles, I often have to use a different set of skills than non-academic reading. Academic language is a form of inaccessibility that I would like to push against by choosing a more literary style of research, creating a findings and discussion chapter through autoethnodrama.

Autoethnography is a needed choice of methodology because it puts the power of research into the hands of the population being researched. Disabled people are marginalized and objectified and may resist research attention (Couser, 2005). This concerns higher education research as well. Disability centered research within higher education conducted by disabled researchers could collect richer data from participants, as they have been on the receiving end of unethical research (Dolmage, 2017). Although I am relatively open about my

experiences with disability, this identity of disability can be deeply traumatic and objectifying to delve into, requiring as much trust to be built within the population as any other culture outside of your own. By choosing an evocative autoethnography, I can share this voice for myself as part of the disabled cultural community without imposing upon others.

With autoethnography your personal stories are research. As is covered in my literature review, the CoDisA population is not covered in much depth or width. Research such as this is wanting to spotlight an existing experience for those who are unaware, as well as to support those who have this knowledge. An additional benefit of choosing this design is that you, the reader, get a personal account from me, a member of the insider group, which is then supported by other research. This is what differentiates autoethnography from a memoir or autobiography. Autoethnography uses the methodology tools and research literature to not only analyze data but consider how others will approach these experiences, and thus make the unfamiliar elements of culture familiar for any reader (Ellis et al., 2011). I hope to make my cultural experience familiar to benefit the following different populations that may crossover:

- Student Affairs professionals
- Faculty at higher education universities
- CoDisA
- Disabled parents
- Individuals who want to learn more about disability

Student Affairs professionals and faculty alike will appreciate the opportunity to learn how my experiences within higher education are framed by my experiences in disabled culture and leverage that to make improvements on campus, or to simply bring into their consciousness that this invisible identity exists. CoDisA will benefit from seeing our identity and experiences

reflected in research, though they might differ or disagree with my experiences because disabled culture covers a wide array of disabilities. Disabled parents will benefit from reading about a grown CoDisA who navigated life and pursued higher education, even though they may not have examples of how children fit into disabled communities at home. Individuals who want to learn more about disability may cross over with any or all of these groups. They will benefit from having a resource where they will receive a social model focused study on disability where they will receive answers to questions that would be intimate to ask someone with a disability directly. I aim to benefit these groups by seeking to contribute to research on this population.

Autoethnography in Practice

This study uses a qualitative approach to describe and analyze the impact of disabled culture on myself as a student in higher education. As this is an autoethnography this places the analysis within my own perspective. As a participant-observer embedded within the culture, my experiences contributed to the structure of the interview protocol and allowed me to delve deeper into examining the cultural influence of my upbringing.

Research Settings

Due to COVID-19 all research was conducted from my one-bedroom apartment in Lincoln, Nebraska, with two cats named Thicket and Burley to keep me company. My desk area is next to my balcony. I write on top of a bright blue yoga ball to try to keep somewhat active. Truly, autoethnography can be conducted as a methodology anywhere since the researcher is also the participant.

Research Tools

Some tools I am using through research are Otter.ai, dictation software on Word, Google Docs, and an ergonomic keyboard.

Data Collection

I have reflected on past and present experience as a student, focusing on being a CoDisA, through the process of interviewing myself. I have reflected upon my past and current experiences as a student during my final years of high school, during my undergraduate at Sonoma State University, post graduate seeking to enter a graduate program, and currently in attendance of University of Nebraska-Lincoln's Master of Arts in Educational Administration with a specialization in Student Affairs Administration. I used the *Pedagogy of the Oppressed* and the social model of disability to guide my data collection, focusing on the ideas of the valuing of oppressed knowledge. I devised interview questions based on these stages of my pursuit of higher education. This includes experiences that I've had within the disabled community: language that we use, how my household functions, and what communication looks like.

The interview questions (Appendix A) were created initially as the sole form of data collection. I asked myself these questions, interviewing myself, which is why I term these as interview questions versus reflective prompts. The interview questions were devised after reviewing the literature and used to guide data collected through written and dictated responses. After coding based on the literature and analyzing the results from this set of interview questions, I determined a second round of data collection was needed to delve further into initial findings. The initial findings related to disabled culture were too broad to address my research questions. The creation of the second round of data collection interview questions relied on these initial findings on disabled culture to guide more relevant data collection to the research questions being asked in this thesis (Appendix B). Data collection was completed through typing responses to interview questions and dictated through Otter.ai.

Data Analysis

Analysis of my data collection was truthfully messy. Due to the lack of foundation, the fact that I am creating this foundation of research, I had a really hard time processing and conveying the information that was relevant to this thesis. I had to continually return to my research questions and the limited research at my disposal, as well as my own experiences. Data responses were printed and coded by hand to find common themes. Initial coding themes were proposed through the literature review, however they evolved as I went through the data. The first round of data analysis was based on finding common words and ideas. The second round of data analysis was conducted after synthesizing the initial coding into larger themes. The codes were written down on a single piece of paper and counted for their frequency to center the most salient aspects of data collection. When I refer to the data analysis being messy, I mean that there is a whole different set of written findings based on that coding that goes into elements of disabled culture that, while not relevant for my research questions, was relevant for my own understanding. Having this set of initial findings, I was able to show my advisor. Giving me feedback on the original findings chapter helped determine the themes that were most relevant to my research questions as I was too close to the material at that point and needed an outside perspective. This is when I did the second round of data collection and re-coded. All data was reanalyzed when the purpose of the study became more focused through the original data collection. I coded the first and second rounds of data collection into narrow categories before more widely grouping them according to my lens and the lens of the literature. My further understanding of my experiences helped find the way to effectively express that to others.

Credibility. Credibility varies based on the type of research. Autoethnography is not traditional ethnography research, though I hope it becomes more popular as we center more marginalized voices within research from the perspective of marginalized voices. Autoethnography shares general traits with qualitative research, as well as unique twists that

lend itself to credibility through rich descriptions, engagement, and social validation. When it comes to autoethnography, credibility is not based within distance from the subject. “[Writings about autoethnography are written] as if they’re written from nowhere by nobody.” (Ellis & Bochner, 2000). My data analysis will not be written from nowhere by nobody. It is centered within myself, my experience, and rooted deeply into the subject. These connections will yield more valid data than someone more distanced (Mertens, 2020, p. 427). I cannot be distant or detached as a researcher when engaging with data yielded from autoethnographic practices, which lends credibility to my research.

Rich, thick descriptions. With the methodology chosen of autoethnography, ethnography requires rich, thick descriptions of culture and situations **to** convey findings. These rich descriptions provide invaluable context to the research. By providing a rich description for readers they can determine if the context of the research fits their needs and interests, increasing credibility (Merriam & Tisdell, 2016).

Prolonged and substantial engagement. Having and collecting sample data from prolonged and substantial engagement involves writing, reflection, and documenting experiences as a researcher (Merriam & Tisdell, 2016, p. 240). I understand disability from an insider perspective. Being an insider means that I’ve been having experiences related to having disabled adults and exposure to disability culture for the entirety of my lifetime. Additionally, though I am an able-bodied person, I also have a disability. My disability is ADHD, and this provides a different layer to my insider knowledge about disability.

Secondarily, I have been contemplating and researching different aspects of this topic since the beginning of my graduate program in Fall 2019, delving more in depth each semester while studying student development and social justice. This is a culminating idea of a project that I have been steadily working towards. With this long term engagement, I have been able to tease out different aspects of the topic that I am able to speak and write to confidently, having

wide and deep knowledge of what literature is available already within the field.

Social validation.

Social validation is the ability to resonate with multiple audiences and makes a significant contribution to larger knowledge (Merriam & Tisdell, 2016, p. 240). The way my research does this is through highlighting an under-researched population and allowing exploration of a topic for future research. Contributing to the larger knowledge is significant, as this is research unlike that I have come across in the field so far, from this perspective and in the field. This topic will resonate across disciplines. It will resonate especially within higher education, with those who study disability, higher education professionals, parenthood, underrepresented populations, disabled adults, CoDisA, and those who study young adult identity development. Writing my findings, I integrated what I know about these groups' experiences and wrote with those audiences in mind.

Lens

This study is one that can be approached from many different theoretical angles. This study will miss the opportunities to have a critical race theory as a lens, as well as other factors that impact disability and higher education, leaving this study open to further research. In the effort of keeping the study simplified I have chosen two theories that will cover disability and education, respectively.

Social Model of Disability. The social model of disability is a theory and a critical lens of the world. Essentially disability is not the issue, which puts the blame on the person for their own disability. The social model of disability argues that disability is only defined by the limitations of the constructed world to be inclusive of differences in minds and bodies. This is the lens I have taken when conducting data collection and review of that data; to ignore this lens in pursuing research, I would be taking a deficit perspective which is already prevalent within

disabled studies. Throughout the analysis of data, the social model of disability appeared frequently even without intentionally using the lens because experiences of disabled culture depended on the world's construction. Many of the negative experiences related to disability which I noted throughout analysis could have been avoided had the world been more adapted. In the design of this study, this idea permeates through the questions, and especially the presentation of findings as there is a set designed to portray adapted, accessible, and inaccessible spaces.

Pedagogy of the Oppressed. The pedagogy of the oppressed is an educational theory that seeks to shift our education model from a banking model to a model that allows for participants to learn through their own experiences, rather than to be told how to think (Freire, 2000). This is an extremely useful lens to take when talking about disability and education because the disabled experience clashes with societally taught norms that we have traditionally "banked." The pedagogy of the oppressed places the educational power back in the hands of minoritized populations, which autoethnography also is well suited to do as a methodology. Placing the belief in minoritized populations to know what is most true about their situations is radical and helps them achieve a further connection to humanity that is methodologically stripped from them by advancing social norms (Freire, 2000). Throughout the analysis of data, I saw this idea reoccur often without intentionally using the framework to investigate due to the overwhelming belief in that this knowledge is valuable and empowered me to rehumanize experiences that were experienced negatively but were intended to be kind from the outside perspective. This lens drives the findings to humanize me as CoDisA and my family. Through autoethnodrama I can show and tell how experiences strip humanity from disabled people, opening the continuous dialogue. I additionally used this lens to inform creating a literal dialogue between characters in the play, researchers, and professionals in the discussion chapter as an example (Freire, 2000).

Limitations

A limitation is that I had to address and survey a wide array of subjects, because the available literature for this project relies more on this study as an exploration, rather than an opportunity to dive deep into the critical disabled cultural lens of a CoDisA. It is important to acknowledge the limitation of time because time limits the amount of depth I can go into for each subject to assess available literature.

Another limitation is that there was a significant portion of time where I was struggling to convey my cultural experience so that non-disabled culture individuals could understand this experience. I was stuck because there were not other people or research which I could readily begin a dialogue with on my specific research question. Additionally, the traditional research presentation of findings was not conveying what I wanted to convey with my findings. Recognizing this limitation, I approached the idea of ethnodrama.

Autoethnodrama: Data Presentation

Ethnodrama is defined as a written play script consisting of dramatized, significant selections from data collection (Saldaña, 2011). I was influenced by theatre that would not define itself as ethnodrama, such as Alison Bechdel's *Fun Home*, Moises Kaufman's *The Laramie Project*, and Eve Ensler's *The Vagina Monologues* (Salvatore, 2017, p. 268). As a reflexive form of ethnography research, this becomes autoethnodrama that will be able to express my experiences and findings more clearly through a non-traditional format. This format serves me well as a presentation of findings due to my own deep interest in the arts, as well as to present these findings in a way that is intriguing and fun for anyone to read, out loud or to themselves. The findings can be presented as the play format it is written in as well, for a different way of engaging with the findings. The discussion chapter is also written in a non-

traditional play format to bring that idea behind a discussion chapter being a conversation between authors, to be presented as a quite literal discussion and dialogue between authors.

Researcher-Participant Reflexivity

I am a 25 year old abled bodied nonbinary woman using both they/them and she/her pronouns who is bisexual, multiracial, and ADHD. I was raised middle class, meaning that our family was comfortable and never had to worry where our next meal was coming from, in San Diego County, California with parents who are physically disabled and use wheelchairs. I have one younger brother as well who is my junior by 4 years, 11 months, and 2 weeks. My mom and brother are also diagnosed with ADHD.

My mom, additionally, has a Master of Arts in Communicative Disorders from San Diego State University, with a specialization in Deaf Education. She taught mod/severe special education, taught me and my brother American Sign Language (ASL) as our first language, alongside English, due to her involvement in Deaf cultural spaces as an ASL interpreter. She currently works in an elementary school as an instructional aide.

My parents are both physically disabled, and I want to highlight the differences in their physical disabilities intentionally. My mother is an incomplete paraplegic. My father is an incomplete quadriplegic. The term “incomplete” designates that they both have more than average movement and feeling that a “complete” paraplegic or quadriplegic would be as is listed in the Diagnostic Manual (DSM). My mom’s paralysis indicates that she has more feeling in her right leg than her left. My father’s paralysis means that he cannot lift his arms up beyond a certain height, but that he is able to manually push a wheelchair of his own volition.

My positionality has allowed me to view disability in contrast to the deficit perspective of disability, which is common throughout disability literature. Having personal experience with disability, both in myself and family members, allows me to understand and view my research in

a positive light, one which encompasses strengths while acknowledging the challenges encountered by having disabilities.

With my background of growing up both with a disability, though undiagnosed until adolescence, and around physical and mental disability, I am biased to approach disability from the belief that disability can be challenging, but it also can have a lot of positive impact. I do not view disability as lacking capability, but that we are in a world of systems and structures that are built to support an idealized, unreachable standard of able-bodied and neurotypical individuals. I also hold the bias that research should be interesting and fill gaps without being essentialist. I think my values and bias will affect my research by motivating me to create something that will add value to the wider realm of higher education research.

Prior to beginning this thesis, I took a course entitled Qualitative Research Methods with Dr. Sarah Zuckerman in Spring 2020, where my final Qualitative Research Project was an exploratory autoethnographic study on being a child of disabled parents. As a class project it did not have to undergo IRB approval. I interviewed both of my parents during this project. This final project was the basis of my prospectus, as this informal research helped me narrow down the subjects I wished to delve further into when beginning my literature review. Due to this previous project and educational journey, I had an understanding and a basis of where to start my research.

Educational Background of Researcher-Participant

Born and raised in sunny, temperate San Diego, California I was able to attend many different school experiences before moving onto higher education. I spell out the following to give a background to where I developed throughout education. My father worked for the San Diego Unified School District as a high-level business and technology administrator for the last 27 years, recently retired, and my mom currently works as an instructional aide for the

Coronado Unified School District. My mom also earned her Master of Arts in Communicative Disorders with a concentration in Deaf Education from San Diego State University in 2006, which was the last cohort of the program.

Schools. I attended many kinds of schools within different districts and areas throughout my life. The list that follows is a description of each of these schools in the order in which I attended them and relevant details of my attendance.

Lafayette Elementary. A small one-story school within the San Diego Unified School District with a garden out back. In 1999 I attended an ASL immersion preschool program at Lafayette due to my mother's work as an ASL interpreter and deep involvement in Deaf culture spaces. This reinforced ASL as my first language and continued my immersion within Deaf culture. I helped grow strawberries in the garden.

Glenn E. Murdock Elementary. This school no longer exists as I attended it, as it now serves a Pre-K through 6th population. When I attended it only served up to the 5th grade. A one-story school within the La Mesa-Spring Valley School District. The population of the school was predominantly white students, teachers, and administrators. The school served mostly middle-class families. There were two playgrounds: one for the younger kids and one for 3rd graders and above that required a steep ramp to descend to the field with various equipment below. I attended preschool through 5th grade at Murdock. When I entered preschool, I first attempted to use ASL and later switched to using exclusively spoken English due to the lack of communication in ASL. There was a small special education classroom with a kind older teacher who was truly excellent at her work. In 2nd grade I volunteered in her classroom in the mornings, mostly feeding the fish and talking with the teacher.

Spring Valley Middle School. This school no longer exists as I attended it. When I attended it was a diverse school area, predominantly white, and serving mostly low-income

students. It was a one-story school with a larger population of students that were then grouped into Sol, Valle, and Mar. I was part of Valle, which later the groupings were renamed for different universities. Valle turned in the University of Washington, as a means to increase interest in the potential of college. I was part of the choir all three years. I do not believe there was a special education program hosted on our campus. Misbehaving was dealt with by isolating students in the In School Suspension room.

San Diego State University. A sprawling Hispanic-Serving institution on a hillside campus with a population of currently around 30000 students. This is a university that I did not attend. My mother earned her Master's in Communicative Disorders with a focus on Deaf Education while I was attending Spring Valley Middle School. I tagged along to many classes with her during her coursework that she was taking and teaching at the time, as well as we did our homework side by side in the evenings. Sometimes I helped her grade ASL 1 quizzes. On nights that my mother was away, my father taught me how to cook. I make a great steak because of this time with him on Thursdays.

Later in my life, after graduating from my undergraduate university, I returned here as a volunteer through my sorority's National Board, while starting an application for the dual master's program of Masters of Public Health and Master of Arts in Latin American Studies at San Diego State University. Through interacting with the many diverse students of Multicultural and National PanHellenic Greek life I found the field of Student Affairs. It was a better fitting field for what I wanted to accomplish with a Master's degree.

Coronado High School and Coronado School of the Arts. At the end of 8th grade my family moved to Coronado, west of La Mesa and Spring Valley by about 30 minutes driving. The school was two stories in a small campus, with different buildings designating different subjects. The oldest building on campus was built as part of the New Deal and hosted the science labs. We had a state of the art turf grass field for athletics, a fantastic theatre for the

performance art programs, ceramic and woodworking studios, and design studios for other programs. The art programs, except for woodworking and ceramics, were mostly run through the Coronado School of Arts which took over the English building from 6th period until 4:30pm every day. I attended this program for musical theatre.

Notably I was diagnosed with ADHD-Hyperactive at age 16, around the same time that my performance and engagement dropped significantly in school. My brother was diagnosed at the same time with ADHD-Inattentive. My mother advocated fiercely on my behalf, and later for my brother, for accommodations that were not easily obtained. The reasons cited were that I had done well in school so far and that I was well-behaved. I later returned to this district after graduating from college as a substitute teacher and instructional aide. They now host a stronger mod-severe special education classroom and transition program. Thankfully they have much improved their stance on accommodations, but it was over half a decade of my mom and other parents fighting for increased representation and flexibility.

Sonoma State University. SSU is located in Sonoma County, well known for its wine production, over 500 miles away from San Diego County and about a 45-minute drive from San Francisco. It was a small public university with a lush green campus. SSU has a predominantly white population of about 8000 students, with a gender divide of 60% women and 40% men, in a suburban area. You could walk from end to end in 20 minutes.

I was a Hutchins (Liberal Studies) major, a program designed for future K-6 teachers centered around reading approximately 20 books a semester, writing essays, and Socratic seminar discussion-based learning. I had no intention of going into teaching or education, but these classes covered all lower division credits except for math in 12 unit classes which met three times a week. I was registered with TRIO and Student Services for Disability on campus but rejected the idea that I was disabled and did not take advantage of accommodations until much later on. The majority of my experience as an undergraduate did not include aspects of

education that I would have needed for my legal accommodations to be applicable. I did not do well in the mainstream courses on campus, but I suffered through them rather than requesting assistance. My senior year is where I was the direct target of ableism. One professor of mine remarked that they didn't understand how I could be so inconsistent at turning in assignments, but so actively engaged in the coursework and material. I had another professor, who was my internship supervisor, actively yell at me for not understanding that I needed to make an appointment during hosted office hours. Then they continued to yell while I was in a state of distress to tell me that I needed to focus and get myself together, because I was unsure if I was going to be able to finish my internship on time in order to graduate. I asked for and used my legal accommodations to extend time on assignments at this point. Both professors wrote me recommendation letters to graduate school. I joined my sorority, Sigma Omega Nu, Latina Interest Sorority Incorporated in my senior year, which became a strong support network for me. I graduated in 2017, with the help of my mom who had many strategies due to lived experience for what to do when your brain and body are working against you in a stressful period of time.

California State Universities International Program - Florence. I studied abroad in my junior year of undergraduate. During my time in Florence, I attended a specific satellite California State University campus hosted in a small two-story building about 20 minutes walking from the center of Florence. This was the first time I saw Student Affairs up close and personal, helping solve potential problems as they came around for students. I also volunteered in a private Catholic elementary school and a public middle school during my time there. It was a very different experience as I encountered students that exhibited signs of learning disabilities and were written off by the end of middle school by their teachers as not being capable of attending college. I enjoyed learning by being surrounded by history and having classes which were less study and more abroad. It allowed me to learn at my own pace, but I also worked to design a schedule that I knew would be consistent and beneficial for me to maintain a

routine. This involved taking four classes taught in Italian the second semester. All homework and readings were in English.

My parents notably decided to not visit while I was abroad due to concerns about accessibility and healthcare if an emergency occurred. Europe is not the most accessible set of countries considering its historical landmarks. My brother, 15 years old at the time, was still able to come visit me. We traveled to 7 cities in 10 days.

University of Nebraska-Lincoln. I am currently attending UNL for my Master of Arts in Educational Administration with a specialization in Student Affairs Administration. UNL is a very large, predominately white land grant institution located in Lincoln, Nebraska. I work with the Nebraska College Preparatory Academy as a graduate assistant, which is a program that serves low-income and first-generation students from four different high schools in Nebraska. The population of this holistic, wellness focused retention program serves largely students of Latinx, Native, and Black backgrounds. I am registered for Student Services for Disability here on campus and I found the process remarkably easy and swift, as I already had an updated diagnosis which I obtained while applying to graduate schools. A large university like this provides many supports to students but may not be well known to students on campus as more first generation students attend.

Summary

In Chapter Three, the choice of autoethnography for the research design and autoethnodrama for presentation of findings were discussed, along with my educational background as part of elaborating on my researcher-participant reflexivity.

This chapter went into depth about the importance of autoethnography as a form of centering and bringing minoritized voices into research. Similarly, autoethnodrama is a way to

convey the findings that make for more accessible reading and provides an immersive experience of the findings.

The researcher-participant section and educational background is provided for context of my educational journey prior to pursuing higher education, as well as the background of my family's educational involvement.

The big ideas to carry through to the reading of the next chapter is that the methodology is the proper choice for this study. I, as the researcher-participant, considered my educational background and the kinds of lens to use for data collection, analysis, and writing, settling on the social model of disability and the pedagogy of the oppressed. This shines through with the presentation through autoethnodrama.

Chapter 4 will be the presentation of findings in the form of an autoethnodrama and is meant to be read or performed. The chapter will cover the spaces and societal interactions which provided the foundation for the critical disabled cultural lens of one CoDisA.

Chapter Four: Findings, or “Up the 5”

The following findings of spaces and societal interactions are presented through autoethnodrama. This autoethnodrama will take you on a college tour trip “up the 5," from San Diego, California, where I was born, to Rohnert Park, California in Sonoma County, which is where I went to undergraduate. The 5 is a major interstate in California. In California, instead of referring to interstates as I-5, we substitute the designation with the word “the."

If the reader is unfamiliar with reading plays, the best practice is to read through the stage directions and dialogues to understand the contexts of each scene. This is especially important as it is likely in the context of this thesis that you will not be seeing this play performed, so you will miss out on important context if you skip this step. There is also an additional dialogue line named “DATA," because at some points I provided a quote directly from the data so the readers could see how the data became the dialogue and scene. This is for context and should not be read as part of the dialogue.

With this background information in mind, please enjoy reading the following autoethnodrama “Up the 5."

“Up the 5” by Amelia-Marie Altstadt

SCENE 1: SPACES ADAPTED, ACCESSIBLE, AND APART

Lights up on a stage with three tableaus. The first tableau on stage right is of a kitchen island, flush with the ground. The second tableau, in center stage, has a gradual rise ramp leading up to it from the left-hand side and another ramp from downstage. On the second tableau, there are desks and chairs and a whiteboard. The third tableau stage left has a gradual rise ramp that meets a single step and a ladder to a platform. YOUNG AMELIA-

MARIE and MOMMA enter from stage left and chase each other around the kitchen island. ADULT AMELIA-MARIE is sitting on a chair on the stage left.

ADULT AMELIA-MARIE

I was raised in adaptable spaces first.

(watches YOUNG AMELIA-MARIE run around the island)

My world was shaped by wheels. When I started going into the world, that was when I realized that the world was built to be different.

(looks as YOUNG AMELIA-MARIE and MOMMA enter the 2nd Tableau)

I didn't understand why that was the case. It was clear to me that my world was better with my momma in it alongside me

YOUNG AMELIA-MARIE has progressed and climbed to the top of the 3rd tableau while MOMMA is making their way through the 2nd tableau and is stopped by the single step.

LIGHTS DOWN:

SCENE 2: TRAVEL TIME

Spotlight up on the 1st Tableau, where you see MOMMA and TEEN AMELIA-MARIE hanging around the kitchen island. There is a duffel bag on MOMMA's lap and one resting unzipped on the counter. Random clothing items and a couple of books are strewn around the stage.

ADULT AMELIA-MARIE

Our one-story house was at the top of a mountain and the bottom of the valley. There was a roll-in shower in the Master bathroom, a ramp in the garage, a low table to fold laundry, and a raised pool in the backyard. The kitchen though was a piece of functional art.

MOMMA

I'm going out to meet Papa in the car. Make sure to lock up on your way out.

(exits stage right)

DATA

"We always had to leave 10 minutes early. Because it took that amount of time to get into the car, pull the wheelchair in the car, turn the car on and get ready to go."

TEEN AMELIA-MARIE

Yeah okay. I just need to pack up a few more things and I'll be right there.

(starts picking up items and shoving them into the duffle bag)

ADULT AMELIA-MARIE

(to the audience)

I miss that kitchen. That granite island in the center of the kitchen is easy to go around and have somewhere to put things down. It was designed, adapted specifically for my family's needs, and it was so beautiful.

DATA

"Like it wasn't built to be a regular kitchen. It was built with their disabilities in mind

TEEN AMELIA-MARIE

(leaning against the island and not picking up items)

I miss this kitchen. You could fill a pot right next to the stove. My parents would take a pot, take it from the stove, put it on the island, and then take it over to the sink, rather than having to cross the kitchen with a heavy pot and go all the way over in one go. Instead of on the wall, like you would usually find a garbage disposal, the switch, it's actually underneath this sink to where you can hit it with your fingers. Similarly, under the stove is where you find another light switch. It made it really easy for me to watch my parents cook for me and learn how to cook myself later on. I make a pretty mean steak.

(remembers that they're supposed to be packing and scrambles to pick up the rest of the clothes, and books, and runs off stage right)

DATA

"We had a very aesthetically pleasing kitchen that my parents remodeled when I was six. But it was all about subverting these expectations. Like it wasn't built to be a regular kitchen. It was built with their disabilities in mind. So instead of on the wall, like you would usually find garbage disposal, it's actually underneath the sink to where you can hit it with your fingers the same time, that's where you also turn on the light underneath the stove rather than it being on the wall. There's an island in the kitchen. Because it's easier to go around the kitchen and have somewhere to put things my parents would take a pot, take it from the stove, put it on the island and then put it over into the sink, rather than having to cross the kitchen with a heavy pot or a hot pot in some cases and go all the way over in one go. But you have to like explore different options there. Also, this is kind of an aside, but it's an example of how accessibility can also be attractive, and like pretty design."

ADULT AMELIA-MARIE

This design subverted expectations of what a kitchen was supposed to look like, built for a different population which also served little me!

(looks down at self)

Well, littler. My family no longer lives in this house but it's still an adapted, beautiful kitchen for anyone to use.

DATA

"I was for a long time before my brother hit puberty, the tallest person in my house. Not actually, my parents are five foot nine. And I'm five foot four. But after a certain age, I was taller than them in their wheelchairs.

TEEN AMELIA-MARIE, MOMMA, PAPA, and LITTLE BROTHER all enter from stage left, the abled-bodied individuals bring on their own chairs and two extra chairs for wheelchair users MOMMA and PAPA to transfer into. They should form what looks like a car, with a large gap in between the four chairs for the wheelchairs to go once actors have transferred into the chairs. TEEN AMELIA-MARIE has one earbud hanging out of their ear, attached to a musical device. They help stabilize the passenger side chair while PAPA transfers and place the wheelchair behind the seat. MOMMA transfers into the driver's seat and turns around in the chair and settles their own wheelchair behind them. LITTLE BROTHER sits in his chair, and TEEN AMELIA-MARIE sits in theirs, placed downstage, and readjusts MOMMA's wheelchair.

ADULT AMELIA-MARIE

My mom's car has its car frame lowered to make transferring from a wheelchair into the driver's seat of the car less strenuous on her upper body.

TEEN AMELIA-MARIE

I wish we were taking mom's car. You can feel every single bump in the road with this Honda Element.

In reverse order, break down MOMMA's car and MOMMA and PAPA get back into their wheelchairs. LITTLE BROTHER takes the extra chairs off stage.

My dad wanted to drive though and driving from his chair is a lot better than having to transfer from his wheelchair into a driver's seat.

PAPA

Hook me in?

LITTLE BROTHER

(mimes hooks and attaches them to the back of PAPA's wheelchair)

ADULT AMELIA-MARIE

My parents' cars were adapted spaces for increased comfort. Cars had, included but not limited to, modified hand controls to assist with steering, gas, and braking. For example, my father switched from a van with a lift to what you see now.

MOMMA

Alright, let's get this show on the road!

TEEN AMELIA-MARIE

Woo.

(takes out and turns on their iPod NaNo, holding their texting phone in the other hand)

"Weightless" by All Time Low plays at a low volume and gets gradually louder (Barakat et al., 2009).

ADULT AMELIA-MARIE

Comfort doesn't only involve physical adaptations to space though, it also includes those environmental aspects of space.

All but Teen Amelia-Marie exit stage left. LITTLE BROTHER takes both chairs off stage.

SCENE 3: RUGBY

"Weightless" transitions into an instrumental version which plays in the background until it fades (Barakat et al., 2009).

TEEN AMELIA-MARIE

(gets up and wanders over to the 1st Tableau and into the 2nd Tableau)

I don't know the last time we left San Diego as a family. Even this trip is kind of last minute. I don't even want to go see any UCs actually, but we might as well. My papa really wants me to go to one, but I'm already set on Sonoma State. There's nothing wrong with a California State school…I have so many memories of being born and raised here- I've never lived anywhere else. It'll be odd to leave, you know if I get in.

MEN, including PAPA, in sports wheelchairs, enter the stage, rugby ball on one of their laps, rushing at each other and trying to grab the ball. YOUNG AMELIA-MARIE enters and cheers and TEEN AMELIA-MARIE exits. ABLED PERSON holds and uses a whistle.

ADULT AMELIA-MARIE

Nothing like seeing your father get knocked over in a chair and hitting the basketball court to get your weekends started. This was a normal Friday growing up.

DATA

"It's kind of like a mix between basketball and rugby to make wheelchair rugby. They would hold the ball on their laps and then she would knock into each other in these sports wheelchairs which are like regular wheelchairs they have wheels that are angled. So that they have more stability. These wheelchair users were talking to each other and knocking each other completely flat on the side.

MAN 1

Pass it here

MAN 2

I'm open! I'm open

ADULT AMELIA-MARIE

I was the only kid there

YOUNG AMELIA-MARIE

(loudly)

Go Papa go!!!

(running around the players/Tableau 2 and trips and falls; starts crying loudly)

Enter MOMMA to grab up YOUNG AMELIA-MARIE and holds them on her lap.

MAN 1

(frustrated)

Shut that kid up!

ADULT AMELIA-MARIE

If you're familiar with kids, you know that that doesn't quite work. The quad rugby community wasn't familiar with kids.

YOUNG AMELIA-MARIE cries louder as MOMMA a YOUNG AMELIA-MARIE exits stage right. MOMMA, PAPA, LITTLE BROTHER, and TEEN AMELIA-MARIE enter from stage right and set up the car.

As we left San Diego, it felt like we were leaving behind a lot more.

SCENE 4: KINDNESS ISN'T ALWAYS KIND

The car moves "forward," images of an open road glide over faces. Suddenly, a clunk is heard as the back of MOMMA's wheelchair falls backward onto TEEN AMELIA-MARIE's knees.

MOMMA

Ah! Damn.

PAPA

What? What's happening?

LITTLE BROTHER

Mom's chair just broke.

TEEN AMELIA-MARIE

(rubbing knees)

Ow, that hurt.

MOMMA

(reaching forward to touch a map display)

I'm going to look up a Home Depot or a bike shop.

ADULT AMELIA-MARIE

And that's how we ended up stopping at a Home Depot in Bakersfield to try to fix my mom's wheelchair.

Take chairs over to the 2nd tableau, and PAPA and MOMMA go up the downstage ramp. ABLED PERSON comes on from stage left. ABLED PERSON chats with PAPA and MOMMA as LITTLE BROTHER and TEEN AMELIA-MARIE sit down at the desks on the 2nd Tableau.

The Home Depot employees were beyond kind. They found the right materials to fix my mom's wheelchair and worked to fix it. Kindness is an integral part of navigating an inaccessible world.

Adult Amelia-Marie goes to climb the ladder of the 3rd Tableau and slips. Young Amelia-Marie grabs their hand and helps pull them up. HOME DEPOT crew pauses and freezes in place.

Thanks.

YOUNG AMELIA-MARIE

You're welcome. It was nothing.

ADULT AMELIA-MARIE

Kindness isn't always kind though.

Young Amelia-Marie climbs down the ladder as Adult Amelia-Marie exits. Abled Person enters on the 3rd Tableau.

YOUNG AMELIA-MARIE

Aunt, what are you doing?

ABLED PERSON

I'm cleaning and helping out. Putting these boxes away.

YOUNG AMELIA-MARIE

(aside to the audience)

Uh, I'm not sure Momma will like that.

(to AUNT)

Okay.

ADULT AMELIA-MARIE

(entering from stage left)

My Aunt was well-intentioned. However, my momma had recently paid someone to take all of those boxes down to where she could reach them.

YOUNG AMELIA-MARIE

Sorry, momma.

MOMMA

(enters from stage right and sighs)

ADULT AMELIA-MARIE

It was fine, but inconvenient and frustrating. Sometimes though, it's plain embarrassing and infuriating, for them and for us.

TEEN AMELIA-MARIE brings a chair for car formation forward for the sighing MOMMA to transfer into, and then one for themselves.

MOMMA

Whoops.

Wheelchair rolls far away downstage as TEEN AMELIA-MARIE gets out of their chair, to grab the wheelchair. Two "helpful" ABLED PERSONS come onto the stage via stage left before they can get the wheelchair. One ABLED PERSON chases after the wheelchair, managing to push it farther away before bringing it back.

ABLED PERSON

(to companion, far on stage left)

Help her! Help her! Help her! Help her!!!

MOMMA

We're fine- I'll get it. No, thank you.

(waves them off)

ABLED PERSONS

No, let us help!

MOMMA

No, I do NOT need your help.

ABLED PERSONS

(to each other, loudly)

Well, that was rude.

TEEN AMELIA-MARIE

(calmly)

They were just trying to help.

MOMMA

(fuming, transferring into the chair)

No, they weren't. They were trying to help themselves look like good people.

MOMMA storms offstage and TEEN AMELIA-MARIE grabs the chairs as they run off after them.

ADULT AMELIA-MARIE

I confess I didn't get it until much later how unkind that experience was and how unnecessary the drama had been. I was trying to deescalate and said the exact wrong thing. Kindness that isn't kind compounds over time.

ABLED PERSON

Alright, you're all set!

PAPA

What do we owe you?

ABLED PERSON

Nothing, you're all good.

MOMMA

Thank you!

TEEN AMELIA-MARIE

That was kind of them.

All family members get back into the car.

ADULT AMELIA-MARIE

Next stop, Santa Cruz.

SCENE 5: SANTA CRUZ

Images of a beachy coast and mountains of Santa Cruz play over the moving car before it stops. LITTLE BROTHER is playing on a DS and TEEN AMELIA-MARIE is staring out the window.

TEEN AMELIA-MARIE

This is really pretty,

LITTLE BROTHER

Yeah.

PAPA

I'm not sure where we can park, so we'll stay here in the car while you explore.

LITTLE BROTHER and TEEN AMELIA-MARIE get out and explore the 2nd and 3rd Tableaus, while the car “idles”.

TEEN AMELIA-MARIE

What's over there?

LITTLE BROTHER

A building.

TEEN AMELIA-MARIE

Cool. Descriptive.

(peeking around)

It's nice.

LITTLE BROTHER

Sure.

TEEN AMELIA-MARIE

I can't really imagine climbing all of these hills at the time.

LITTLE BROTHER

There's a bus.

TEEN AMELIA-MARIE

Yeah, but not always. I'm done looking honestly. Let's go back to the car.

MOMMA

How'd you like it?

TEEN AMELIA-MARIE

It was nice, I guess. Lots of hills. I think those were the dorms.

ADULT AMELIA-MARIE

Residence halls.

(sheepishly)

The student affairs professional in me now couldn't resist.

PAPA

Alright, let's get going then for dinner. Tomorrow we'll be at our final destination.

ALL exit, take down the car.

SCENE 6: CALLOUS COMPANIONS

ADULT AMELIA-MARIE

All that happened reminded me of how inaccessible everything is, and how some people go out of their way to make things more uncomfortable.

YOUNG AMELIA-MARIE appears on the top of the 3rd Tableau with YOUNG ABLED PERSON. MOMMA is with ABLED PERSON in the 1st Tableau, chatting.

YOUNG ABLED PERSON

Why are your mom and dad in wheelchairs?

YOUNG AMELIA-MARIE starts to climb down the ladder while responding.

YOUNG AMELIA-MARIE

(well-practiced, kind of bored)

My mom was in a car crash and my dad in a fire.

DATA

"I learned about my parents' disabilities from them. They only ever told me the short versions though. I had my explanation down pat. People always ask me. They would never ask my parents. They would ask me. I said my mom was in a car crash and my dad was in a fire.

YOUNG ABLED PERSON

(smug, looking down at YOUNG AMELIA-MARIE)

Your dad wasn't in a fire.

YOUNG AMELIA-MARIE

(looks up sharply)

What? How would you know?

YOUNG ABLED PERSON

I heard everything from your mom. She was talking to my Abuelita, but I know Spanish. Your uncle killed your grandparents, your aunt, and tried to kill your dad with their Boy Scout Hatchet.

DATA

"My dad's story though is quite simply a tragic event. I learned about it not from my own parents but from the girl that I had an on-again-off-again friendship with. My mom didn't know she was being listened to. She didn't know this girl knew Spanish as she was talking to the girl's grandmother who spoke only Spanish. almost immediately friend ran to me to tell me this story. I hardly even believed her."

YOUNG ABLED PERSON

(with glee and watching YOUNG AMELIA-MARIE closely)

That's so messed up. They didn't even tell you.

YOUNG ABLED PERSON exits before YOUNG AMELIA-MARIE can say anything back. ABLED PERSON talking with MOMMA exits as well, as MOMMA goes to the 2nd Tableau.

YOUNG AMELIA-MARIE

That can't be true.

MOMMA

Amelia- it's time to go!

YOUNG AMELIA-MARIE

(solemnly)

Hey, momma. I have a question...

ADULT AMELIA-MARIE

I was 10 there. Actually, just before I started trying to go by Amelia-Marie. I knew that being in a fire couldn't be the whole story, but that's the version my parents told me, and they said I could know more when I was older. My "friend" framed it like it was kindness- that I should know the truth about my father, but it wasn't her truth to tell. This entitlement to my family's story is forced intimacy. Forced intimacy is stigma in action, defined as being pressured or coerced to have to reveal personal information to have access to basic resources or accommodations. It is also reflected in the idea that non-disabled people feel entitled to know and share things about their personal traumas and medical history. This was one of the most egregious things, but more often than not I would get-

ABLED PERSON and YOUNG ABLED PERSON appear on the 3rd Tableau. TEEN AMELIA-MARIE looks up from their journal.

ABLED PERSON

How did your parents get in their wheelchairs?

YOUNG AMELIA-MARIE

(turning from 2nd Tableau)

My mom was in a car crash and my dad in a fire.

ABLED PERSON

Oh, that's so sad.

(exits)

YOUNG AMELIA-MARIE

...no, it's not.

YOUNG AMELIA-MARIE hugs MOMMA before they exit off stage.

YOUNG ABLED PERSON

Are you adopted?

TEEN AMELIA-MARIE

No.

YOUNG ABLED PERSON

You're not? How do your parents have sex?

TEEN AMELIA-MARIE

(disgusted)

Why would I know? Why would I want to know?

YOUNG ABLED PERSON, chasing after, TEEN AMELIA-MARIE, disgusted, exit.

ADULT AMELIA-MARIE

All before the customary exchange of "how are you?" and "fine" took place.

SCENE 7: SONOMA STATE SPACES

TEEN AMELIA-MARIE writes in their journal in the car.

ADULT AMELIA-MARIE

Arriving at Sonoma State University was a relief after visiting the University of California, Santa Cruz.

TEEN AMELIA-MARIE

(closes journal and puts earbuds in)

SSU will be better. Hopefully.

The car "stops" smoothly. ALL exit the car and make their way, splitting into the 1st and 2nd Tableau.

TEEN AMELIA-MARIE

(smiling brightly, looking around)

I want to go see the English building! Oh, and the bookstore!

ALL wander around the 1st Tableau and 2nd Tableau, exploring and chatting with each other silently as they look around.

ADULT AMELIA-MARIE

This was the first campus that my parents, in their wheelchairs, had been able to get out and explore with my brother and me. The sun was shining so brightly. I was feeling light-hearted. My favorite college from the websites was also a place that welcomed my family.

MOMMA and PAPA travel alongside LITTLE BROTHER and TEEN AMELIA-MARIE, who traveled up the steps and explored the 3rd Tableau.

Of course, there were still hiccups, like how the elevator wasn't built to fit more than one wheelchair, but nothing we couldn't manage.

TEEN AMELIA-MARIE gets behind PAPA, LITTLE BROTHER in front, and helps him in the wheelchair hop the step. MOMMA turns back to explore the 2nd Tableau, and LITTLE BROTHER goes with her.

TEEN AMELIA-MARIE

So, this is the English department. I wonder if anyone is around today?

PAPA

Let's go see.

ABLED PERSON enters from 3rd Tableau and climbs down the ladder to meet TEEN AMELIA-MARIE and PAPA.

TEEN AMELIA-MARIE

Hi! Do you work here? My name is Amelia-Marie and I'm planning on applying to Sonoma State soon. We want to know more about the school and everything.

ABLED PERSON

(with a bright smile)

Yes, I do. I'd be happy to help. What questions can I answer?

LIGHTS FADE TO BLACKOUT:

Summary

In Chapter Four, you experienced an autoethnodrama with data sourced from my experiences growing up as a CoDisA. This play took place along the 5, an interstate in California, while on a road trip with disabled parents and my younger sibling to look at different potential colleges to apply to in the fall.

Through this autoethnodrama you were able to experience the spaces and societal interactions I experienced, such as experiences with kindness, forced intimacy, stigma, and the ways physical space made me feel at home or like a stranger, and more. These are the big ideas from this chapter to take into the final chapter of this thesis.

Chapter 5 is a continuation of the autoethnodrama in the form of a “talkback” that invites dialogue between characters and readers.

Chapter Five: Discussion, or Act 2: "Up the Five" Talkback

Tableaus remain part of the set as actors bring out their chairs to sit in front of the audience of people. The actors featured in this talkback are ADULT AMELIA-MARIE, TEEN AMELIA-MARIE, and YOUNG AMELIA-MARIE. Those asking questions and responding are scattered and placed throughout the audience.

YOUNG AMELIA-MARIE

Hi! Welcome to the talkback! We're so glad to have you remain past the show!

TEEN AMELIA-MARIE

Yeah, it's nice to be here. We're also lucky enough to have our playwright be here for the talkback, as they also play the role of Adult Amelia-Marie.

ADULT AMELIA-MARIE

It's a delight to be here. We'll get started with our first question from the audience.

(points to an audience member with their hand raised)

Yes, you.

RESEARCHER

When you were deciding which scenes to include in the work, what did you see validated during your research?

ADULT AMELIA-MARIE

That's a great question to start with. Why doesn't Young Amelia-Marie start?

YOUNG AMELIA-MARIE

Corrigan and Watson was my favorite from what was written before and was part of this play! They talked all about courtesy stigma, which is what you saw in Scene 4: Kindness Isn't Always Kind.

ADULT AMELIA-MARIE

Courtesy stigma, the stigma placed on those associated with disability in this case, discussed in Corrigan and Watson was validated by these findings, as the play showed the experiences of assumption and discomfort that abled individuals had around especially Young and Teen Amelia-Marie when it was seen or mentioned that our parents use wheelchairs.

TEEN AMELIA-MARIE

Where I was most validated was with the 2019 article by Krauss and Olkin when they wrote findings about how being surrounded by more of a disabled community decreased the amount of courtesy stigma a CoDisA like me felt. They also mentioned in the article about teens like me not viewing experiences as negative when asked, for example, getting something off a tall shelf that my parents couldn't reach. It was one of the only research articles that directly talked about people my age and I could see myself in the research.

ADULT AMELIA-MARIE

I agree, I never thought negatively of what it meant to help my parents out. I think this shows clearly in Scene 7: Sonoma State Spaces and Scene 2: Travel Time. It was part of the process, not particularly worth noting often via the text, but you can read some moments in the stage directions.

TEEN AMELIA-MARIE

Most of the time our parents didn't need help, but it was never a big deal to help when they asked. Krauss and Olkin showed that this was the same for other teens with disabled parents.

YOUNG AMELIA-MARIE

That's so true!! We also talked a lot about Greer, because he was one of the few disabled people that talked about his kids- like me.

ADULT AMELIA-MARIE

As a researcher, he was very clear about having age-appropriate tasks for children, but also that it built more independence in general at an earlier age. We showed this in Scene 5: Santa Cruz, as well as in the final scene.

TEEN AMELIA-MARIE

Santa Cruz was a good example of both an age-appropriate thing and independence. My brother and I were comfortable in getting out and exploring without our parents since there wasn't like a place for them to really go with us.

ADULT AMELIA-MARIE

The final scene- I want to draw to how it validates and adds detail to Greer's take on independence. Back when I was a young teen, I didn't have any issues walking up and asking for the support I needed. The show ends on the note of asking the student affairs professional we met for help and them offering information in return.

YOUNG AMELIA-MARIE

Thanks for the question!

ADULT AMELIA-MARIE

Yes, thank you- next up.

RESEARCHER 2

What was in conflict with your findings while writing this show?

ADULT AMELIA-MARIE

Honestly, there wasn't much conflict between the findings and previous literature.

TEEN AMELIA-MARIE

(surly)

Mostly because there wasn't any...

ADULT AMELIA-MARIE

There is that. Also, the research we found was so general that it could be applied across fields. My findings assist us in finding more specific items related to being a CoDisA to work with in the future. I hope someday there are more conflicts between this research and future research when we are able to tease out the intricacies of being a CoDisA through exploring a range of other disabilities in adults.

TEEN AMELIA-MARIE

Honestly, it was super frustrating to not have that much previous research to go off of. I think the only thing that we really had any conflict with were the theoretical perspectives.

ADULT AMELIA-MARIE

Don't get me started on McRuer.

RESEARCHER 2

Who is McRuer?

ADULT AMELIA-MARIE

Alright, you've got me started. He created crip theory. The reason I did not use this theory as a framework for my research, opting instead for the social model of disability and the pedagogy of the oppressed, is that it's a slur against the disabled being used by a non-disabled person.

TEEN AMELIA-MARIE

It also deals with queerness, and we didn't really need that framework for this study.

ADULT AMELIA-MARIE

The other framework is the deficit model of disability.

YOUNG AMELIA-MARIE

There's nothing wrong with my parents. They're just like everyone else.

ADULT AMELIA-MARIE

Exactly, so I never would have used that one either as a framework. I read crip theory to form an opinion about why I didn't prefer to use it to the social model of disability. As a theory talking about the intersections of queerness and disability, crip theory is an incredible foundational theory. For my purposes, it just didn't fit with the needs of the study. The social model of disability was everything I wanted in a framework without the problematic elements.

Social model of disability helped me to frame disability intentionally in contrast to the deficit model, which places the onus of disability on individuals, to place the onus of disability on systems. Freire additionally with the pedagogy of the oppressed validated the learning I had done with disability prior to learning the academic terms. I always knew something was off with

some negative experiences, like in Act 1, Scene 4: Kindness Isn't Always Kind, but I didn't really pinpoint that some of those experiences were dehumanizing at the time. Freire helped put those experiences in perspective.

(sees another hand up in the audience)

Oh, yes, what's your question?

STUDENT AFFAIRS PROFESSIONAL

Hello, I'm a student affairs professional locally. Having seen the show, what do you recommend for the audience to take into our profession and practice?

YOUNG AMELIA-MARIE

Go Big Red! (Insert team mascot of local university if known)!

STUDENT AFFAIRS PROFESSIONAL

(laughs)

Thank you!

ADULT AMELIA-MARIE

That's an excellent question.

I think the very first recommendation we have is to evaluate what the spaces on campus are saying to your scholars and their families. For example, even as Sonoma State in the final scene was dramatically more accessible in comparison to the mountainous UC Santa Cruz for wheelchair users due to the design of the campus, we still ran into the issue of limited elevator space. The limited elevator space communicated the assumption that wheelchair users do not travel with other wheelchair users.

Some additional questions to get your mind moving: Do you have instructions on how to get into buildings via the accessible entrances readily available, or do instructions assume someone is nondisabled? Do you know where accessible restrooms are, and how to get to them?

Inclusion done right is not having to ask for accommodations to access space on campus.

YOUNG AMELIA-MARIE

I'd like it if people stopped asking rude questions out of curiosity.

ADULT AMELIA-MARIE

Thanks, Young Amelia-Marie. That's a great recommendation for practice. Challenge your desire for information about someone's disability. Is it necessary information for you to have, or is it curiosity? Have you treated them as a person, or have you skipped to potentially asking questions that could be inappropriate, hurtful, or traumatic? Remember- someone's disability could have come out of a traumatic event, like my dad's story I shared within this play. As a young kid, I often had to field these questions about my parents' personal lives. This stigma in action is called forced intimacy.

TEEN AMELIA-MARIE

I used to be happy to answer questions, but it gets annoying to hear people dehumanize my parents like that. Being disabled is a big part of who they are and how they lead life, but that's not their sole interest in life. Ask my Papa about scuba diving or HAM radios, or my Momma about her writing or when she owned a home care company.

ADULT AMELIA-MARIE

Basically, if you wouldn't typically ask intimate questions of a stranger, it's not appropriate to ask those same questions of a disabled person or those close to them. Especially

with no prior conversations or follow through. This is an opportunity to also educate others on how to prioritize humanizing others over your own curiosity.

STUDENT AFFAIRS PROFESSIONAL

Thanks, that makes sense. I have a follow up- why did you choose to focus on disabled culture?

ADULT AMELIA-MARIE

Disability as part of diversity and inclusion efforts is often overlooked. So overlooked, in fact, that the only services for disabled people on campuses are usually accommodation offices like Student Services for Disabilities. Remember, if a disabled person has to ask for an accommodation that's not inclusion. Our multicultural centers rarely center on disabled experiences as a culture, due to unawareness. Disabled students, family, staff, faculty, and so forth all need the cultural and social support on the campus of disabled culture which goes beyond compliance with the law. My recommendation is to first ask what supports regarding disability that are not compliance-related are on campus? Does your multicultural office on campus, or individual office, highlight disability as diversity?

STUDENT AFFAIRS PROFESSIONAL

Makes sense- thank you! One last question, what is something we could start doing today that would improve campuses for CoDisA and their families?

TEEN AMELIA-MARIE

Not assuming that people are all abled tbh.

YOUNG AMELIA-MARIE

People were always so shocked. They either responded with pity or curiosity when I told them about my parents. If you respond with pity, that's my biggest pet peeve.

TEEN AMELIA-MARIE

It's all part of dehumanizing my parents, looking at them as if something is lacking. There's nothing lacking about our family.

ADULT AMELIA-MARIE

I definitely prefer when people approach with curiosity rather than pity- disabled isn't a bad word.

TEEN AMELIA-MARIE

Yeah! It isn't! Doing your own research on why "disabled" isn't a bad word to the disabled culture and community is important.

ADULT AMELIA-MARIE

Getting your office to jump on board with replacing euphemistic language like "differing abilities" with preferably identity first language, but person first language is fine as well, is a big win. Person first language is "person who uses a wheelchair." Identity first language is saying "autistic person," "disabled woman," or "Blind man." The language shift may be small, but it will make a big impact on CoDisA and anyone holding or developing a disabled identity on campus. Not everyone who holds a disability identity will use identity-first language, so be ready to change your language to what that person prefers for themselves, but it is best practice. On a personal level, evaluating the language you use on a daily basis is also important. Start by swapping out words with an ableist connotation with something similar. For example, instead of "crippling" you can say "debilitating." Instead of "crazy," or "insane," you can say "wild." It's

subtly inclusive and helps to dismantle those deficit frameworks. You'll also be pretty shocked with how many words with a negative connotation are disability related.

STUDENT AFFAIRS PROFESSIONAL

That's pretty cr- oh I see what you mean. That's wild, I mean.

ADULT AMELIA-MARIE

Yeah- don't feel bad when you try! It takes time! I think we have time for maybe one more question before we need to finish up this talkback. Yes, you in the front row.

RESEARCHER

Where do you think research should take us in the future?

TEEN AMELIA-MARIE

Like Krauss and Olkin, I just think that like we should do more research focusing on the CoDisA population from the CoDisA perspective and not the parents' perspective. Like, we could expand to focus groups where one group talks about the impact of one disability and another group talks about being around another kind of disability growing up.

ADULT AMELIA-MARIE

What they mean is acquired disabilities, like my parents', or congenital disabilities, those like Greer who had cerebral palsy. As someone who wrote this thesis because they did not see representation for CoDisA in the Student Affairs field, or really any field talking about this specific population, there's a lot of directions to go from here.

I think I would be most excited to see research that investigates more in-depth about the cultural elements developed by growing up in a disabled household.

YOUNG AMELIA-MARIE

Like kindness- does it mean something different to me rather than nondisabled people?

TEEN AMELIA-MARIE

What is the impact on first-generation students who also hold a CoDisA identity? My Momma has a bachelor's, but she did her degree nontraditionally over the course of 10 years and my papa never completed a four year degree.

ADULT AMELIA-MARIE

Those are both very good ideas! Kindness would be interesting to explore from the perspective of a CoDisA, because kindness has a very different connotation with disability. It can be necessary to navigate through the world, like when my mom got her chair fixed at Home Depot in Scene 4, or it can be remarkably detrimental to access, like later in Scene 4 where the intention was to help by picking things up, but actually that kindness made things a lot more difficult in the long run. I think also, with the ideas of independence early on and the additional comfort with asking for support, what impact does that cultural identity have on being a first-generation student? Are CoDisA more or less equipped to navigate systems of higher education than another first-generation student? I call myself first-gen-ish. My mom was more equipped to help me with my Master's than my undergrad.

I think this research could go a lot of different directions but starting with cultural elements would be great.

TEEN AMELIA-MARIE

I think I'd like to hear about DisCrit more as a lens or framework. I understand that Adult Amelia-Marie didn't use it due to time constraints, but we're not only white.

ADULT AMELIA-MARIE

It's true- I identify as mixed and think disability studies is predominately white. So, I'd love to bring that into future studies. When we address minoritized identities, we can't analyze them solely through one identity. That works for research, but not so much for real life experiences.

YOUNG AMELIA-MARIE

Thanks for coming!!

ADULT AMELIA-MARIE

(laughing)

Yes, unfortunately that was our last question. However, I look forward to the future discussions involving this play and the future implementation of practice or research our readers, you, will do soon in the future. Thank you again for being here!

ALL

Bye! Have a great day!

ALL GRAB CHAIRS, BOW, AND EXIT OFF STAGE.

Summary

In Chapter Five, you experienced the continuation of an autoethnodrama with data sourced from my experiences growing up as a CoDisA. This play took place along the 5, an interstate in California, while on a road trip with disabled parents and my younger sibling to look at different potential colleges to apply to in the fall. Chapter 5 featured an after show talkback with the characters of Young, Teen, and Adult Amelia-Marie.

Chapter 5 discussed the thoughts of each character in relation to relevant literature. Most of the literature available on CoDisA was validated by Chapter 4's findings, those questions having been asked by Researchers in the audience.

A Student Affairs Professional asked what could be put into practice, with the response being to engage in further reading, use identity-first language, consider what spaces are telling CoDisA and their families, as well as not participating in forced intimacy.

The Researcher followed up and asked about future directions for research. Since this is an emerging field, and this research is intended as a foundation for future research, it can take many different directions. Some of the suggestions were to see how disabled culture interacts with kindness or first-generation CoDisA students.

The big ideas from this chapter are to continually improve your understanding and investigation of disabled culture and put into practice what you have learned. Additionally, this is not the conclusion of CoDisA research, but a foundation for anyone to take, challenge, and expand upon in the future.

Chapter 5 ends with a joyful goodbye, with a hope for implementation of this research in practice or research in the future.

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Appendix

Appendix A

Interview Protocol A: Child of Disabled Adults

1. When did you realize your upbringing was different?
2. How did I find out that my experience was different than an able-bodied family?
3. How informed was I about disabilities?
4. How did I learn about my parents' disabilities?
5. What was it like when other people learned about your parents' disabilities?
6. How did adults in your life treat you afterwards?
7. How did your peers treat you?
8. What elements of your home were different from friends' places?
9. What rituals did you engage in when arriving at places outside of the home?
10. In what ways did your parents support your development as an able-bodied person?

Interview Protocol B: Undergraduate at Sonoma State University

11. What was the transition like from high school to undergraduate?
12. How did your parents assist you in reaching college?
13. What support did you have in undergraduate?
14. Was your pathway clear?
15. Describe my experience in choosing dorms.

Interview Protocol C: Postgraduate seeking to enter a graduate program

16. What was the experience of moving back home after graduation?
17. What were the expectations upon living at home?

Appendix B

Interview Protocol D: Additional questions based on initial findings

1. In what ways do my parents model asking for support?
2. What ways do my family and I embrace disabled community?
3. In what ways was independence fostered as I grew up and went away for college?
4. How did my parents model being proactive?
5. How is exploration part of disability culture?
6. What is part of my parent's trauma? Did they pass that trauma onto me?
7. What do I mean when I say kindness can be a trauma?
8. When was there an incident where kindness was shown to be traumatic, rather than helpful as intended?
9. What do I value as difference? How did I come to that conclusion?
10. How does that affect how I interact within higher education?
11. In what ways do I actively include others?
12. What spaces do I perceive as accessible? How do I feel in accessible spaces versus inaccessible spaces?